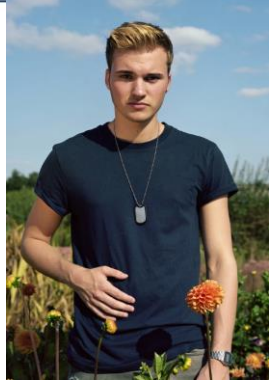

Beyond the Cass Review: New Clinical Practice Guidelines and Ethical Recommendations in Youth Transgender Health Care across Europe

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How do we debate,
if we agree to disagree?



Respect+

The Cass Review

Context, defined tasks, requirements for the entrusted person and resulting limitations

I. Task:

„ ... commissioned by NHS England to make recommendations on how to improve services provided by the NHS to children and young people who are questioning their gender identity or experiencing gender incongruence and ensure that the best model for safe and effective services is commissioned. “ (Cass Interim Report 2022, p.15)

II. Requirements for the entrusted person

Facing the complexity of the task together with the given context of both professional and political controversies around issues of transgender health care, it was intentionally commissioned as **Independent Review.**

QUESTION: *What exactly is meant by independence here?*

Examples of Independent Reviews in the UK



Commissioning state authority	<ul style="list-style-type: none"> • Andrew Lansley – Secretary of State for Health and Social Care 	<ul style="list-style-type: none"> • Department for Education 	<ul style="list-style-type: none"> • Boris Johnson (Prime Minister)
Services	<ul style="list-style-type: none"> • Healthcare Commission (HCC) 	<ul style="list-style-type: none"> • Public child & youth welfare 	
Question	<ul style="list-style-type: none"> • Serious neglect of care and supervision 	<ul style="list-style-type: none"> • Improving children’s social care and supervision 	<ul style="list-style-type: none"> • UK’s response to the Covid-19 pandemic
Person entrusted	<ul style="list-style-type: none"> • Robert Francis, Sir/Barrister 	<ul style="list-style-type: none"> • Josh MacAlister/ school teacher and funder charity 	<ul style="list-style-type: none"> • Baroness Heather Hallett, /Barrister
Field	<ul style="list-style-type: none"> • Healthcare 	<ul style="list-style-type: none"> • Children’s Social Care 	
Expertise	<ul style="list-style-type: none"> • Clinical Negligence, Mental Health & Capacity, Professional Discipline 	<ul style="list-style-type: none"> • Management and training of child and youth welfare professionals 	<ul style="list-style-type: none"> • Lady Justice of Appeal
	<p>Mid Staffordshire NHS Foundation Trust Public Inquiry 2013</p>	<p>Review of Children’s Social Care 2022</p>	<p>Covid inquiry 2022</p>

II. Requirements for the entrusted person

- In previous Independent Reviews, reviewers' independence from the services to evaluate was assured, however, combined with the entrusted person's acknowledged expertise within the field at target.
- Independence from specialist expertise in the sense of viewing a complex subject area "from the outside" had formerly not been defined as a required quality feature.

And what about.....

- independence from conflicts of interests?

no disclosure of COI in the Cass Review

- independence from politics and preset political agendas?

**Sir Sajid Javid**

Secretary of State for
Health and Social Care
(2021-2022,

„I became Secretary of Health in June 2021 ... the NHS had already began an independent review into the GIDS service by Dr Hilary Cass. She was getting close to publishing her interim report, so she had a lot of findings and so I wanted to meet with her and I asked her to do so. And what I was hearing here was that you were getting these young people presenting themselves to the NHS saying I think I am a girl living in a boy’s body or vice versa and instead of questioning, whilst taking this tentatively, it was an affirmative, a completely affirmative approach, it was a self-diagnosis. This was a huge scandal. As soon as I heard all of that I felt that something had to be done. I met with NHS leaders, and I started the process of shutting down the Tavistock.“

What are the facts as adequately documented in the Cass Review?

Data on treatment trajectories of the GIDS patient population Apr 2018 – Dec 2022

- *“Overall, **27% of patients were referred to endocrinology.**”*
- *“A higher proportion of patients referred to endocrinology are aged 15-16years.”*

(Cass Review 2024, Appendix 7, p. 9)

“The qualitative research will capture a diverse range of trajectories experienced by gender-questioning children and young people, exploring a range of different experiences and outcomes. This will include talking to children and young people and their families/carers who are currently negotiating gender-related distress, young adults who have gone through the process of resolving their distress and care professionals.”

(Cass Review Interim Report 2022, p. 74)


The Qualitative Study made for the Cass Review by York University

Original research



OPEN ACCESS

'Letting him know that we love him': the experiences of young people who question their gender and the parents who support them

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ABSTRACT

Background Gender identity services for children and young people are currently being reorganised in England and Wales. Provision is required to negotiate clinical uncertainty and a public debate that cannot agree on what care should look like.

Objectives To explore how young people, parents and young adults respond to gender dysphoria, distress or discomfort; and to understand how they negotiate referral, assessment and possible interventions.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Gender identity services for children and young people negotiate clinical uncertainty and public controversy. NHS support is currently being reorganised.
- ⇒ There is uncertainty about what an appropriate model of care should look like.
- ⇒ The experiences of young people and their parents, by prioritising what matters to them

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► <http://dx.doi.org/10.1136/archdischild-2024-327992>

III. Limitations

- Despite its acknowledged merits in providing a comprehensive view into the field and its holistic approach, the Cass Review cannot be taken as, nor replace **medical practice guidelines** according to international **standards in evidence-based medicine**.
- **This has never been claimed to be the case!**

To set the records straight:

*„There should **be consistent treatment protocols or guidelines in place**, in order to make sense of variations in outcomes. Where possible, these should be compared between and across multiple different centres.“*

(Cass Interim Report, 2022, p.65)

How has the European multidisciplinary professional community of transgender health care addressed the task of updating evidence-based and consensus –based standards of patient-oriented care since 2024?

How do we understand evidence-based medicine?

"Scientific medicine is not the same as evidence-based medicine. Evidence-based medicine is the conscientious, explicit and judicious use of current best external scientific evidence to inform decisions in the medical care of individual patients. The practice of evidence-based medicine is the integration of individual clinical expertise with the best available external evidence from systematic research. Evidence-based medicine is based on three pillars: individual clinical experience, the values and wishes of the patient and the current state of research."

Before any clinical recommendations can be drawn from reviewing the best available evidence, a critical appraisal of the evidence from the perspective of clinical expertise and experience is an independent essential second step in any process of guideline development.

Evidence base for off-label prescriptions in paediatric and adolescent medicine (*Meng et al. 2022*)

82% of all current treatment recommendations in medical guidelines on off-label prescriptions are based on **uncertain to very uncertain evidence**

Recommended *best practice* as the treatment method of first choice can nevertheless be justified by (e.g.):

- Sufficient evidence for adults has been proven
- Sufficient patient safety in children and adolescents in other areas of application has been proven
- Lack of proven treatment alternatives
- Non-prescription would be ethically unjustifiable

NEW RECOMMENDATION DOCUMENTS SINCE 2024

Document	Type	Editorial / Commissioning Body	Authors
Cass Review (2024)	Independent Review	NHS England	One independent pediatric expert (H. Cass)
SUI – NCE Ethical Opinion Paper (2024)	Ethical opinion paper	Swiss National Advisory Commission on Biomedical Ethics (NCE)	14 members of the commission
FRA - SFEDP Practice Guideline (2024)	Practice guideline (endocrinology)	French Society of Pediatric Endocrinology and Diabetology (SFEDP)	19 members of a working group
EUR - ESPE / Endo-ERN Expert Opinion	Expert statement (ped. endocrinology)	European Society for Pediatric Endocrinology (ESPE) / European Reference Network for Rare Endocrine Conditions (Endo-ERN)	12 members of a working group / thematic group
POL – Multidisciplinary Framework Guideline (2025)	Comprehensive consensus-based practice guideline	Polish Sexological & Psychiatric Associations & Polish society of Pediatric Endocrinology	44 members of an expert panel
GER – AWMF certified S2k Guideline (2024)	Comprehensive consensus-based practice guideline	Association of Scientific Medical Societies in Germany (AWMF)	24 authors mandated by professional societies each

AGREE-II

- Internationally acknowledged gold standard tool for guideline appraisal in medicine (Brouwers et al., 2010)
- AGREE scores correlate positively to both patients' and clinicians' endorsement (ibid.)

1. Scope and Purpose

1.3 (...) to whom the guideline is meant to apply is specifically described.

2. Stakeholder Involvement

2.1 The guideline development group includes (...) all relevant professional groups.

2.2 The views and preferences of [patients] have been sought.

3. Rigour of Development

3.1 Systematic methods were used to review the evidence.

3.3 Methods for formulating the recommendations are clearly described.

3.4 Health benefits, side effects, and risks have been considered (...).

3.6 The guideline has been externally reviewed by experts prior to its publication.

4. Clarity of Presentation

4.1 The recommendations are specific and unambiguous.

5. Applicability

5.5 The guideline provides advice for implementation in the health care context.

6. Editorial Independence

6.2 Competing interests (COI) have been recorded.

Did the guideline development group include individuals from **all relevant professional groups**?

Recommendation Document	Criterion
Cass Review (England)	<ul style="list-style-type: none"> – Single authorship of a “consulting pediatrician” appointed by the NHS England. – Relevant other groups were involved in consultation format, but not as co-authors. – Members of “Cass Team” were not disclosed.
SUI – NCE Ethical Opinion Paper	National advisory commission on Bioethics with different professions (medicine, philosophy, law...)
FRA - SFEDP Practice Guideline	Members were appointed by SFEDP & „for specific points, collaboration with specialists from other medical disciplines was sought”
EUR - ESPE / Endo-ERN Expert Opinion	Members were those who served on the Steering Committee of the ESPE Working Group on Gender Incongruence and members of Endo-ERN main thematic group on Sexual Development and Maturation from centres that reported seeing >20 transgender adolescents per year.
POL – Multidisciplinary Framework Guideline	Multidisciplinary expert panel <i>Plus:</i> „ Specialists working with adolescents with gender dysphoria and gender incongruence had the opportunity to join the group at every stage of the work.”
GER – AWMF certified S2k Guideline	Each member was officially mandated by a medical or psychotherapeutic professional society (child & adolescent psychiatry, pediatrics, endocrinology, sexology, medical ethics, psychotherapy

Were **systematic methods** used to review the evidence?

Recommendation Document	Criterion
Cass Review (England)	<ul style="list-style-type: none"> – External systematic and preregistered reviews (York University) until 2023 with clear documentation of inclusion and exclusion criteria, – criteria were partly changed after preregistration and are partly unequal for different interventions
SUI – NCE Ethical Opinion Paper	Reliance on other guidelines, no own systematic reviews
FRA - SFEDP Practice Guideline	Unsystematic reviews
EUR - ESPE / Endo-ERN Expert Opinion	Unsystematic reviews
POL – Multidisciplinary Framework Guideline	Unsystematic reviews
GER – AWMF certified S2k Guideline	<ul style="list-style-type: none"> – Own systematic reviews until 2020 with documentation of inclusion and exclusion criteria, – coverage of 2021-2023 by incorporation of three recently published high-level systematic external reviews (<i>NICE 2020a&b; Taylor et al. 2024a&b; Zepf et al., 2024</i>)

Are the **methods for formulating the recommendations** described?

Recommendation Document	Criterion
Cass Review (England)	No such methodology reported & single authorship (no consensus)
SUI – NCE Ethical Opinion Paper	After a process of comprehensive discussion „This document was unanimously approved.”
FRA - SFEDP Practice Guideline	“Each chapter was prepared by one to three authors [...], and it was then reviewed and revised by the group as many times as necessary to achieve a consensus position.”
EUR - ESPE / Endo-ERN Expert Opinion	“Each section was prepared by 1-2 authors [...]. Sections were then discussed with all authors during online and face-to-face meetings and adapted where necessary until final approval.”
POL – Multidisciplinary Framework Guideline	„The final version of the document was accepted by all the authors of the guidelines.”
GER – AWMF certified S2k Guideline	<ul style="list-style-type: none"> – Structured consensus conferences with external moderation & opportunity to submit dissenting opinions – documented consensus strength for each single recommendation one-by one (> 95% for almost all)

Has a draft version been **externally reviewed** by experts prior to its publication?

Recommendation Document <tho< th=""> <th>Criterion</th> </tho<>	Criterion
Cass Review (England)	No external review
SUI – NCE Ethical Opinion Paper	According to the NOC Statutes no external review shall be undertaken (State of Committee's Authority in Bioethics)
FRA - SFEDP Practice Guideline	"The final version was reviewed by four external reviewers."
EUR - ESPE / Endo-ERN Expert Opinion	"The draft document was [circulated] to representatives from [community organizations] for review. The subsequent version of the manuscript was reviewed by the ESPE Clinical Practice Committee."
POL – Multidisciplinary Framework Guideline	„The guidelines were consulted and recommended by [one community organization]" & comments were submitted by external experts in endocrinology and medical law
GER – AWMF certified S2k Guideline	<ul style="list-style-type: none"> – Transparent online (<i>Lime Survey</i>) consultation phase after first draft (March 2024) exclusively open to members of the 28 involved organizations (incl. 2 patient organizations) – All received comments and their appreciation in the draft revision are published in Methods Report – External review and certification of Methods Report through AWMF institute – Revised version with some modified recommendations was finally approved by the 28 executive boards of each participating organization prior to final certification and release through the AWMF (awmf.org)

Have competing interests been recorded and addressed?

Recommendation Document	Criterion
Cass Review (England)	No disclosure of COI & co-contributors explicitly not disclosed
SUI – NCE Ethical Opinion Paper	COI are disclosed for each individual member of the commission
FRA - SFEDP Practice Guideline	COI are disclosed for each individual author
EUR - ESPE / Endo-ERN Expert Opinion	COI are disclosed for each individual author
POL – Multidisciplinary Framework Guideline	No disclosure of COI
GER – AWMF certified S2k-Guideline	<ul style="list-style-type: none"> – COI are disclosed for each individual author and contributor – structured management of COI (e.g. exclusion from chairing a chapter group)

COMPARING OVERVIEW According to AGREE Standards

Recommendation Document	<i>Scientific recommendation documents without guideline claim or standard</i>		<i>Medical Guidelines</i>			
	Cass Review NHS England	NC Ethics (SUI)	SFEDP (FRA)	ESPE (EUR)	Sexol/Psychiatr/Endocrin SOC (POL)	AWMF (GER)
Representation of disciplines	0	++	+	+	++	+++
Evidence reviews	+++	0	+	+	+	++(+)
Formulation of recommendations	0	++	++	++	+	+++
External review of guideline	0	0	++	+	++	+++
Mangement of COIs	0	++	++	++	0	+++

Opinion no. 43/2024

Bern, 7 November 2024

Medical treatment for minors with gender dysphoria

Ethical and legal considerations

Opinion Paper of the Swiss National Advisory Commission on Biomedical Ethics (CNE)

Download:





Background of the Swiss CNE

nek-cne.admin.ch

- Inaugurated in 2001 by the Federal Government based on the law on human reproduction and legal enactments
- Regarding to topics and working procedures **independent** from the Ministry of The Interior and Ministry of Health
- 15 members from diverse professions (ethics, medicine, law, social sciences economy, nursing sciences, natural sciences)
- elected for a maximum of 3x4 years, personally appointed by the Government
- Current president: Prof. Dr. theol. Markus Zimmermann Vice president: Prof. Dr. med. Samia Hurst-Majno



Medical treatment (6)

12 recommendations

Research (3)

Social context (3)

1. Medical key recommendations

01

Access to high-quality interdisciplinary care and counselling must be assured

02

Treatment decisions are to be based on the individual indication

03

No proxy consent for irreversible body modifying treatments

04

The decision-making process is to be open and participatory

05

Pathologisation of the people concerned is to be avoided

06

If necessary, institutional clinical ethics bodies should be used to support decision making

2. Research

Existing gaps in research should be identified and closed

The precautionary principle does not justify rejection of treatment on principle

Social factors are to be systematically taken into account in studies of the effectiveness of treatment

3. Social context

Gender is to be understood as a graded spectrum

Social recognition of a specific gender identity should be decoupled from body-modifying treatments

Public outrage over this issue harms the people concerned and jeopardises evidence based medical care



AWMF – S2K GUIDELINE



GENDER INCONGRUENCE AND GENDER DYSPHORIA IN CHILDHOOD AND ADOLESCENCE



<https://register.awmf.org/de/leitlinien/detail/028-014>



Vereinigung für analytische und tiefenpsychologisch fundierte Kinder- und Jugendlichen-Psychotherapie in Deutschland e.V. gegr. 1953



Trans-Kinder-Netz e.V.

AWMF – S2K Guideline

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Practice guidelines

Endocrine management of transgender adolescents: Expert consensus of the french society of pediatric endocrinology and diabetology working group

ARTICLE INFO

Keywords:

Transgender adolescent
Hormonal treatment
GnRH analogs

ABSTRACT

Introduction: Requests for hormonal transition in minors are increasing. To date, there is no national recommendation to guide these practices in France. Therefore, the SPEDP (French Society of Pediatric Endocrinology and Diabetology) has commissioned a group of experts to draft the first national consensus on this topic.



Endocrine Management of Transgender and Gender-Diverse Adolescents: Expert Opinion of the ESPE Working Group on Gender Incongruence and the Endo-ERN Main Thematic Group on Sexual Development and Maturation

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Framework guidelines for the process of caring for the health of adolescent transgender (T) and non-binary (NB) people experiencing gender dysphoria — the position statement of the expert panel

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To conclude

- The Cass Report and the accompanying international debate after its release have stimulated a remarkable process of updating high-level evidence-based and consensus-based medical guidelines in professional societies and among experts in the field of transgender health across Europe.
 - Since 2024, our new evidence- and consensus-based guidelines and ethical standards have substantially been developed further according to recognized scientific professional standards
-

How do we continue to debate?

THANKS!